Internal Revenue Service P.O. Box 2508 Cincinnati, OH 45201

Department of the Treasury

**Employer Identification Number:** 

Contact Person - ID Number:

**Contact Telephone Number:** 

Date: December 1, 2011

Release Date: 2/24/2012

Number: 201208037

LEGEND

UIL 4945.04-04

B= disease

C= disease

w= number

x= dollar amount Y= grant program

## Dear

We have considered your request for advance approval of your grant-making program under section 4945(g)(3) of the Internal Revenue Code, dated June 16, 2011.

Our records indicate that you were recognized as exempt from federal income tax under section 501(c)(3) of the Code and that you are classified as a private foundation as defined in section 509(a).

Your letter indicates that you will operate a grant-making program called Y.

Y will provide funding enabling individuals selected to create a clinical information and biosample database and repository (collectively the "Biobank") to enable discovery of pathogens and pathogenic mechanisms in B.

You intend to make grants to clinicians working with B patients and research scientists to allow them to contribute to the study and treatment of B by engaging in one or more of the following research areas:

a. Establishing a rigorously-characterized group of subjects including individuals diagnosed with B and healthy controls;

b. Obtaining clinical data and biologic samples from these subjects for

storage in the Biobank; and

c. Administering the management and research use of Biobank data and biologic samples, in particular for use in investigating the role of microbial and immune factors in the pathogenesis of B by applying molecular tools for identification of pathogens and profiling of host responses.

You expect to award a minimum of w grants and that each grant will be in the amount of approximately x dollars. Each grant will be in an amount designed to cover the reasonable costs of the applicable study and, where studies involve human subjects research, will be pursuant to a protocol approved by an Institutional Review Board.

There is no formal application process or similar procedure being used. Your executive director and board chair will confer with professionals in the medical and scientific research fields to identify eligible recipients for the grants. Eligible recipients will include clinicians with significant numbers of B patients and research scientists, with preference given to those who are participating in the recent National Institutes of Health-sponsored C study in relation to B.

Grant recipients will be chosen from among those identified individuals based on their expertise, interest and accomplishments in working with B patients and their expected contribution to the Biobank of biosamples and medical information. Recipients will be selected by your executive director and board chair in consultation with appropriate medical and scientific research professionals based on the qualifications of the potential grantee.

Members of your selection committee will not be in a position to derive a private benefit, directly or indirectly, if certain potential grant recipients are recommended or selected, as the case may be over others. No grants will be made (i) to your substantial contributors; (ii) to your directors or officers; (iii) to any member of the selection committee; (iv) to any family members of any of the persons in clauses (i) through (iii); or (v) to any other disqualified persons. In additional, no grants will be made for a purpose that is inconsistent with your charitable, educational, and scientific purposes.

The terms and conditions of each grant will be contained in a grant agreement executed by you and the grant recipient. These terms will include: a description of the specific purpose of the grant (one or more of the three purposed listed above); its duration; the amount to be paid under the grant; and the requirements for periodic and final reports to you, including the due dates for the reports.

Grant recipients must use best efforts to complete the study within the one year term. There are no specific procedures for renewal or extension of the grants, although the grant agreements may be amended by written agreement of the parties.

If for any reason a grant recipient is no longer available to continue the study, they must notify you and if a mutually acceptable successor is not identified within sixty days, the grant agreement may be terminated by you on no less than fifteen days notice.

If the grant agreement is terminated prior to the completion of the study; (i) subjects may no longer be enrolled in the study and all study activities must terminate; (ii) upon your request, the grant recipient must provide complete reports for all subjects that have been entered into the study as of the termination date and write a final report for that portion of the study that has been completed as of the termination date; and (iii) the grant recipient must provide you or its

designee with any and all research information in its possession, and all clinical specimens collected under the study. Upon termination of the agreement prior to the completion of the study, you may, at your discretion, pay the grant recipient a pro-rated amount for actual work performed and reimburse expenses that are incurred before notice of termination is received, and which cannot thereafter be canceled.

Grant recipients will be required to submit a report at specified periods, which will be a least once each year, detailing the use of the grant funds and the progress the grant recipient has made. Upon final expenditure of grant funds, recipients will be required to make a final report describing their accomplishments with respect to the grant and accounting for all the funds received.

If reports to you, or other information, including the failure to submit reports after a reasonable time has elapsed from the report due date, indicate all or part of grant funds are not being used for their intended purpose, you will initiate an investigation.

If you determine that any part of a grant has been used for improper purposes, you will take all reasonable and appropriate steps to recover diverted grant funds or to insure the restoration of diverted funds and the dedication of other grant funds held by the grant recipient to the purposes being financed by the grant. These steps will include withholding any remaining disbursements of funds until you have received (i) the grant recipient's assurances that future diversions will not occur and (ii) any delinquent reports from the grant recipient. These steps will also include, if necessary, legal action unless such action would in all probability not result in the satisfaction of execution on a judgment.

You will retain records relating to all grants made pursuant to these procedures for a period of at least four years after each grant is completed. Such records will include a list showing the name and address of each grant recipient, a description of the expenses funded by the grant and reports received from the grant recipient.

You agree to maintain records that include the following:

- (i) Information used to evaluate the qualification of potential grantees;
- (ii) Identification of the grantees (including any relationship of any grantee to you);
- (iii) The amount and purpose of each grant; and
- (iv) All grantee reports and other follow-up data obtained in administering your grant program.

Sections 4945(a) and (b) of the Code impose certain excise taxes on "taxable expenditures" made by a private foundation.

Section 4945(d)(3) of the Code provides that the term "taxable expenditure" means any amount paid or incurred by a private foundation as a grant to an individual for travel, study, or other similar purposes by such individual, unless such grant satisfies the requirements of subsection (g).

Section 4945(g) of the Code provides that section 4945(d)(3) shall not apply to individual grants awarded on an objective and nondiscriminatory basis pursuant to a procedure approved in advance if it is demonstrated that:

- (1) The grant constitutes a scholarship or fellowship grant which is subject to the provisions of section 117(a) and is to be used for study at an educational organization described in section 170(b)(1)(A)(ii);
- (2) The grant constitutes a prize or award which is subject to the provisions of section 74(b), if the recipient of such prize or award is selected from the general public, or
- (3) The purpose of the grant is to achieve a specific objective, produce a report or similar product, or improve or enhance a literary, artistic, musical, scientific, teaching, or other similar capacity, skill, or talent of the grantee.

Section 53.4945-4(c)(1) of the Regulations provides that to secure approval, a private foundation must demonstrate that:

- (i) Its grant procedure includes an objective and nondiscriminatory selection process;
- (ii) Such procedure is reasonably calculated to result in performance by grantees of the activities that the grants are intended to finance; and
- (iii) The foundation plans to obtain reports to determine whether the grantees performed activities that the grants are intended to finance.

Based on the information submitted and assuming your award programs will be conducted as proposed, with a view to providing objectivity and nondiscrimination in making the awards, we have determined that your procedures for granting the awards comply with the requirements contained in section 4945(g) of the Code and that awards granted in accordance with such procedures will not constitute "taxable expenditures" within the meaning of section 4945(d)(3).

In addition, we have determined that awards made under your procedures are 'scholarship or fellowship' grants within the meaning of sections 4945(g)(1) and 117 of the Code, and are excludable from the gross income of the recipients subject to the limitations provided in section 117(b) of the Code, including to the extent that such grants are used for qualified tuition and related expenses within the meaning of section 117(b)(2) of the Code.

This determination is conditioned on the understanding that there will be no material change in the facts upon which it is based. It is further conditioned on the premise that no grants will be awarded to foundation managers, or members

of the selection committee, or for a purpose that is inconsistent with the purpose described in section 170(c)(2)(B) of the Code.

The approval of your award program procedures herein constitutes a one-time approval of your system standards and procedures designed to result in awards which meet the requirements of sections 4945(g)(1) and 4945(g)(3) of the Code. This determination only covers the grant programs described above. Thus, approval shall apply to subsequent award programs only as long as the standards and procedures under which they are conducted do not differ materially from those described in your request.

Any funds you distribute to individuals must be made on a true charitable basis in furtherance of the purposes for which you are organized. Therefore, you should maintain adequate records and case histories so that any or all award distributions can be substantiated upon request by the Internal Revenue Service.

This determination is directed only to the organization that requested it. Section 6110(k)(3) of the Code provides that it may not be used or cited as a precedent.

You must report any future changes in your grant making procedures. Please keep a copy of this letter in your permanent records.

We have sent a copy of this letter to your representative as indicated in your power of attorney.

If you have any questions, please contact the person whose name and telephone number are shown above.

Sincerely yours,

Lois G. Lerner Director, Exempt Organizations

Enclosures: Notice 437 A copy of the redacted letter